Noticing in Neurology

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Abstract

Know how to listen and you will profit even from those who talk badly.

Plutarch

Despite a recognition that diagnosis has the potential for harm as well as good ‘getting it right’ remains a source of considerable pride for neurologists. The increasing use of investigation centred methods has demoted foundational clinical skills in some medical specialities but the interview has retained its primacy as the most useful diagnostic instrument in neurological practice. Disease and disability usually co-exist but one of the great fascinations of medicine is how the same disorder can cause remarkably different illness experiences. Patient’s stories are not always easy to listen to and may be equally difficult to tell. The way words are spoken, the pauses and hesitations, what is not said, and the accompanying gestures and expressions all assume great importance during history taking. The application of probabilistic logic, critical thinking, knowledge the use of mental short cuts and experience are then required to transform the patient’s narrative into a working diagnosis.

How to Learn to Listen

On my second medical firm I had the opportunity to watch an expert listener at work. In the nineteen sixties Wallace Brigden was one of Britain’s leading cardiologists and like almost all his colleagues on the staff at The London Hospital he was an Oslerian (Figure 1). His students were expected to be in attendance ten minutes before the start of clinic and on arrival he would give us a nod before sitting down at the desk. After reminding the sister-in-waiting that he must not be interrupted except for an emergency he would then rise, walk to the door and call the first patient in. After introducing himself he would usually start with a
few pleasantries before asking what it was that had prompted the patient to see her general practitioner. Leaning forward slightly in his chair he would then listen to the presenting complaint with a lowering or raising of his inquisitive eyebrows. His eyes rarely strayed from the patient’s face as he listened in silence. When the patient stopped talking he would sometimes re-state what he had heard to minimise his assumptions. He might then ask one or two open questions like, ‘Can you say a bit more about the pins and needles in your left shoulder?’, Can I go back to when… or with a squeezing gesture of his hand ‘so the pain was heavy and constricting?’ He would then pause, open the case notes, read the letter of referral and write down the salient aspects of the presenting history. In his relaxed, unflustered way he would then elicit the past medical and family history and conclude the interview with no more than three or four plain questions relating to aggravating and relieving factors of the presenting symptom its severity, duration and radiation. It was usual for him to probe beyond the purely physical especially in people recovering from a heart attack. His eyes never gave away his thoughts about the diagnosis to either the patient or us.

After he had completed the examination and concluded the consultation he would often turn to us and ask if we had any questions. He would then try to put into words how he had determined that the patient’s symptoms had arisen from the heart. His analytical approach always made sense once he had explained it. At the end of clinic he encouraged me to go to the wards and listen first hand to his patients stories, write up what I remembered then read what I had recorded back to the patient. As a cardiologist who always had a stethoscope in his hand he understood better than most the value of listening. Medicine was a personal science and by involving me he got me to understand. For Wallace Brigden time at the bedside was never wasted.

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Despite his well-known adage ‘Listen to your patient, he is telling you the diagnosis’ Osler wrote much less on how to take a medical history than he did on the other foundational skills of observation and examination. A medical interview also requires versatility, empathy, good communication and patience. Joseph Conrad wrote that. ‘Half the words we use have no meaning whatever and of the other half each man understands each word under the fashion of his own folly and conceit’. Listening with a third ear to the patient’s story requires great sensitivity, intuition and awareness and is not easily achieved.

The courage to listen.
Attending to a patient’s story is an art that is not readily mastered and one that takes practice and experience. I place the patient a little to the left at an angle to my desk and ask the family to sit further back to remind them who is the centre of attention but at the same time observe their facial expressions. As I listen to the patient’s story I try to suspend all frames of reference and avoid jumping to conclusions. I focus as attentively as if I was listening to a riveting lecture but vary my eye contact based on intuition. I try to create trust by conveying a sense of genuine interest. At the same time I am constantly floating hypotheses in my head and keeping an eye out for odd or discordant information. When the patient has finished giving the story I say nothing for a few moments in the hope that the silence will bring further revelations. I then try to clarify and summarise the information with some questions in the interests of coherence and completeness and to clarify the effect of the symptoms on the patient's ability to function. When I am uncertain what is going on I sometimes ask, “What do you think is causing the problem? and when I suspect a hidden agenda related to fear I ask “Do you have any particular concerns about this?” or if it is a patient coming for a second opinion “what are you hoping from this visit? I seek clarification when terms like migraine, numbness and cramps are used. I ask questions to help me unpack gathered information if I suspect that the patient has telescoped separate similar symptoms into a single event. Accurate recall of the past medical history and family history is variable and may need further corroboration from family members I write down what I hear and then read it back because it improves my understanding, where it seems appropriate I even quote the patient’s own words in the notes. In coming to a diagnosis I try to guard against biases such as framing and anchoring, try not to railroad the patient or let my remembered clinical experience mask the evidence. I then re-intensify my focus on verbal clues that might unmask worries or other undeclared symptoms

As I have matured I have come to understand that symptoms as well as neurological signs can be hard or soft, and group in characteristic diagnostic clusters and patterns. Most days I also encounter at least one new presentation of a common disease or come across symptoms that are not part of a classic textbook description of organic disease. Many of the complaints I hear about do not have medical names. I have learned through my mistakes and those of colleagues that patients with mental illness can also have new physical symptoms and co-morbid neurological disease.

By the end of the medical history I have usually gained sufficient information to reduce uncertainty to a level where the examination is unlikely to provide major surprises.
Sometimes I am sufficiently certain of what’s going on that I do not need to order any additional tests. If I am still uncertain after the interview I occasionally bring the patient back and go over the story a second time. In the days when Osler and Brigden taught at the bedside there was no Google or Dr House to educate the public about diseases or medical terminology. The ubiquity of computer generated information has meant that many patients now include explanations and theories in their narrative. The internet is also a potent generator of health anxiety which can in turn lead to the elaboration of symptoms in the worried well in a desire to be ‘helpful’

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The following three vignettes are examples of how the medical interview continues to reveal the cause of illness when all other approaches have failed.

**A Fly in the Ointment**

In 1976 after a brilliantly argued paper by David Marsden spasmodic torticollis changed from a functional disorder to an adult onset focal dystonia and as a consequence became more neurological and less psychiatric. Shortly after this taxonomical volte-face I was asked by my mentor Gerald Stern to carry out a trial with bromocriptine, a dopamine agonist because one of his patients with torticollis had responded to L-DOPA. At her first consultation a 56 year old woman who had volunteered for the trial told me that her painful tilted neck had been caused by her husband’s mental and physical cruelty. I took note of what she had said but I remained convinced of Marsden’s inductive premise. I continued to see her from time to time in clinic after the trial was over and in 1979 after missing two successive appointments she re-appeared in handcuffs accompanied by a prison warden. She told me she was awaiting trial in Holloway jail for the manslaughter of her husband. Despite her serious predicament she no longer wore the customary despairing look on her face and the posture of her neck was markedly improved. ‘Doctor the pain in my neck was my husband’ and it has now all gone’ she told me. During the clinical trial I had been more focused on whether I could detect an improvement in her neck than her theory as to the causation of her movement disorder but I took great notice now and five years later reported in ‘the green rag’ (JNNP) a spontaneous remission rate of 15 per cent in adult onset cervical dystonia. Her story has
stayed with me as a reminder that most medical diagnoses are little more than insecure and therefore temporary conceptions.

**The Bugle of a Black Swan**

23 years ago, a forty two year old Pole from Gdansk who worked as a plumber was referred to me at the Middlesex Hospital complaining of a subacute onset of stiffness and slowness that had been present for about six weeks. As soon as I called him in from the waiting room it was obvious he had Parkinsonism. He had reduced blinking, a stolid facial expression, a tremor at rest of his left hand and a monotonous voice. On repetitive finger tapping he had a progressive slowing of speed and amplitude that was more evident on the left than right. His posture was hang-dog, his arms were held stiffly by his side and he walked slowly with a mild shuffle. The patient’s story and the accompanying referral letter gave me no clues as to the likely cause. I organised a MR head scan and started him on L-DOPA (Madopar 12.5mg/50mg tds). I advised him to double the dose after a week if he had experienced no side effects and fixed an appointment for him to see me again in eight weeks.

On his return he strolled in from the waiting room and with a smile on his face informed me that he was cured. The only abnormal sign I could now find was mild cogwheel rigidity at the left wrist. When I expressed pleasure but some surprise at the turn of events he told me that his girlfriend had asked him to ask me whether the Chinese herbs he was taking for stress and high blood pressure and which he had not felt important to mention at the first consultation might be relevant to his case. He then showed me a small white cannister with Chinese writing on it that he had bought from San Lings on Goodge Street close to the hospital. Although I felt a causal relationship was very unlikely I accompanied him to the shop where the owner told us that the herbal medicine was called verticil in English and that it was made from the roots of Rauwolfia species (Figure 2). Reserpine, the alkaloid present in the roots of many of these evergreen shrubs is known to deplete brain catecholamines and was marketed fifty years ago in the West as an antihypertensive before it was realised that depression and iatrogenic Parkinsonism were side-effects.

I advised the patient to stop taking the herbal medicine and to tail off his L-DOPA gradually over the next four weeks. At final follow up he was fully recovered without the need for long term dopaminergic replacement.
Tunnel Hearing

In 1999 the distraught wife of one of my patients told me in clinic that the apomorphine injections I had prescribed for her husband had turned him into a junky. He had begun to eat his L-DOPA medication like sweets and was ‘shooting up’ more than ten times a day. He had also started to binge eat, cross dress and act out sexual fantasies. She went on to say that sometimes he would disappear and be brought home in the early hours of the morning suspected by paramedics or the police of ‘crack dancing’. When confronted with his wife’s story Mr C denied everything. I explained to both of them that I had never encountered acute craving to anti-Parkinsonian medication but advised Mr C to restrict his rescue apomorphine injections.

A week later the patient’s wife sent me a letter in which she requested I admit her husband for detoxification. Since we had met her husband had become financially extravagant, emotionally callous and seemed to be most of the time ‘on cloud nine’. She implied that I had not taken her concerns as seriously as I should have done in clinic and was desperate. It was only after a second similar case came to light a few weeks later that I accepted her story and realised I had been guilty of overconfidence. If the dopaminergic system in the ventral striatum was important in modulating pleasure and reward then why couldn’t anti-Parkinsonian dopaminergic drugs subvert homeostasis in the same way as cocaine and amphetamines? This led to the publication of a paper entitled Hedonic Homeostatic Dysregulation in Parkinson’s disease and a research programme to understand what were the risk factors for ‘DOPA addiction’.

These case histories illustrate that the cause of a neurological disorder is rarely presented on a silver plate and that the unheard obvious can have serious repercussions. Patients, and their families and nurses if given the opportunity to speak not only tell you the diagnosis but reveal hitherto unrecognised phenomena, hidden agendas and even contribute new insights into the mechanisms of disease.

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The failure to listen started with doctors who were compelled by governmental agencies and health insurers to see more patients in less time. This started to undermine the
importance of ‘high touch’ medicine and in some specialities has had the effect of reducing
the medical history to a series of closed questions and tick boxes sometimes supplemented by
a litany of scales with spurious numbers administered in the waiting room by nurses. As
health technology with its veneer of certainty has advanced patients have become ever more
desperate to be heard and recognised.

The fact that statistical methods including the use of likelihood ratios and probability
calculations have provided support for the belief that the medical interview remains the most
efficacious method for making an accurate diagnosis support a case for its reimbursement at a
rate at least double that paid for a MR head scan.

As I have slowly lost my grip on the latest medical literature I have become a much
better listener and probably a better neurologist. Although I still take pride in my clinical
acumen and consider a missed diagnosis or a false label as a serious error I better appreciate
the impact illness has in rupturing a patient’s hopes and dreams. It is not only in searching for
diagnostic clues that listening is important but also in coming to understand the reasons that
lie behind a patient’s treatment preference. Neurology must always begin with the
circumstances of the case colourful, lively and frequently not without pain and that the lives
of those who present with neurological symptoms are far more richly detailed than their
misfortune suggests. Being heard is a transformative ritual that facilitates healing.

Further reading

Bernard Lown. The Lost Art of Healing: Practising Compassion in Medicine. Ballantine

Michael Glynn and William Drake Editors, Saunders Elsevier 2012

References

Joseph Conrad quote from a letter written to Cunninghame Graham in 1898.

Legends

Figure 1  Dr Wallace Brigden in the 1960’s (Bart’s Health Archives and Museums)
Figure 2 (a) San Ling’s in Goodge Street.

2 (b) the box of Shegen mu root capsules (Rauwolfia serpentine)